

Commentary

Is the Slippery Slope Steeper for People With Disabilities?

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Before individuals with disabilities won civil rights, they were called invalids. According to *Webster's Dictionary*, an invalid is without value, defective, and weakened—just like Jenny Morris, the successful 33-year-old British politician described by Silvers,* who found after she sustained a spinal cord injury that “in the eyes of others, her life no longer seemed worth living.” Or like U.S. vice-presidential candidate Franklin Delano Roosevelt who had a new social identity thrust upon him when he contracted polio in 1921. “Now he is a cripple,” said a friend of his mother, “will he ever be anything else?”¹ Suddenly devalued, they might have resonated with this social bias and wondered whether they would be better off dead than alive and disabled. However, each went on to disprove stereotypes and to live productive lives, Morris as mother and social activist, and FDR as the only four-time President of the United States.

Might there be a connection between the beliefs about the perceived invalidity of persons with disabilities and that fact that, in addition to individuals with terminal illnesses, many of Dr Jack Kevorkian's assisted suicide cases might have had disabilities? Silvers outlines a broad spectrum of views regarding such physician-assisted suicide among the 50 million members of the U.S. disability community.²

Some disability rights activists contend that, if physician-assisted suicide is to be added to American civil rights, then they are entitled to the same freedom of choice, autonomy, self-determination, and access to this medical service as all other Americans. Anything less, or different, they would view as discriminatory, an infringement upon hard-won freedoms. They would like a long, happy, and productive life and a peaceful, comfortable, assisted death. They believe that “legalization and the potential for abuse are apples and oranges, separate issues requiring separate remedies.”³

Other disability rights leaders have expressed concerns that such rights may endanger the lives of disabled people who would not wish to commit suicide, but who

may feel compelled by social or economic pressures to hurl themselves down the “slippery slope.” They point to centuries of stigmatization and devaluation of the lives of people with disabilities, culminating in the murder of more than 70,000 disabled persons declared “useless eaters” by Hitler.⁴

A common theme in the debate is a concern about the inequality of power between physicians and patients, and the “frailty and porosity of the medical ethic in the face of social pressures.”⁵ It is argued that, since many professionals and the societies they represent have historically expressed profound ambivalence toward people with disabilities, the slippery slope may be steeper and more lethal for this stigmatized group, so that assisted suicide may become a convenient rationing tool, or an alternative to providing life-enhancing services.⁶ In other words, that it may become easier to dispose of disabled people than to meet their needs for living fulfilling and meaningful lives.

According to Camus, “there is but one truly serious philosophical problem, and that is suicide. Judging whether life is or is not worth living amounts to answering the fundamental question of philosophy.”⁷ In the case of judging quality of life, it is disturbing to find that the medical literature lacks clarity and consistency in defining or measuring quality of life.⁸ Even more disturbing for people who develop disabling conditions is the realization that ambiguous, inadequate, and often biased quality of life assessments have the power to influence critical decisions made by health care providers. For example, while 86% of individuals with high-level quadriplegia report that they have average or above average quality of life, only 17% of emergency providers believe that this can be so. Significantly, 17% of physicians, 28% of nurses, and 34% of emergency medical technicians would act on their prejudices, and would not perform or support emergency intervention to ensure the survival of a person after C3/4 subluxation.⁹ In other words, when health care professionals think they themselves would not want to live “like that,” they feel justified in letting their patients die. “The bird thinks it is an act of kindness to give the fish a lift in the air.”¹⁰

*See also “Protecting the Innocents—People With Disabilities and Physician Aid-in-Dying” by Anita Silvers, MD, on pages 407–409 of this issue of THE WESTERN JOURNAL OF MEDICINE.

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Silvers suggests that perhaps for those who turn to Dr Kevorkian, "controlling one's death represented the lone remaining way to exert control."² If that is true, we must search energetically for healthier alternatives to enhance our patients' self respect, support their civil rights, autonomy and freedom of choice, within a life-affirming model. To quote Dr Albert Schweitzer: "The tragedy of life is not in the fact of death itself. The tragedy of life is what dies inside a man while he lives."¹¹

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